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ABSTRACT

A work group convened by the Director of the U.S. Office of Maternal and Child Health examined the need and opportunity for a continuum of care to serve vulnerable populations of pregnant women and infants, and made recommendations for improving linkages among the various services needed by these mothers and their infants. Barriers to linkage between and among prenatal, perinatal, followup, referral, and early intervention services were noted. The work group recommended: standardized data collection among agencies concerning indicators/predictors of poor pregnancy and developmental outcomes, feedback to health care providers who make referrals to early intervention programs, prenatal and parenting classes for expectant parents, provision of community services information to parents prior to hospital discharge of their newborns, effective preservice and inservice training, collaboration with media to disseminate information, etc. An appendix indicates the lead agency that each state has designated for implementation of Public Law 99-457, Part H, and outlines the legislation's 14 components essential to a comprehensive system of care for children from birth to 2 years and their families. (JDD)

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Linkages

Continuity of Care for At-Risk Infants and Their Families: Opportunities for Maternal and Child Health Programs and Programs for Children with Special Health Needs

Report of a work group convened in Washington, D.C., February 1-2, 1988 by Vince L. Hutchins, M.D., Director, Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resources Development

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Bureau of Maternal and Child Health
and Resources Development

Health Resources and
Services Administration
Rockville MD 20857

Dear Colleague:

I am pleased to enclose a copy of the report of a work group convened in February by the Office of Maternal and Child Health. The report was developed with two goals in mind:

- To examine the need and opportunities for a continuum of care approach which addresses vulnerable populations of pregnant women and infants; and

- To make recommendations relative to improving linkages between the various services needed by these mothers and their infants.

The timing of the meeting was designed to build on the momentum of a number of recent events, including the Surgeon General's initiatives on behalf of children with special health needs, and the passage of P.L. 99-457, that are related to improving the well-being of infants, toddlers, and their families. We feel that this summary of discussion at the meeting and the recommendations developed by the group will be useful to State Maternal and Child Health/Services for Children with Special Health Needs (MCH/SCSHN) Program Directors, lead agency contacts for Part H of P.L. 99-457, Federal and State Interagency Coordinating Council members, other agencies, individuals, and organizations that are working to respond effectively to family needs by focusing new resources and assuring effective linkage of services.

The MCH/SCSHN Programs have a tradition of service to children and families that is more than half a century old. We look forward to identifying and using new opportunities for improving linkage between prenatal, infant, and early intervention services in the years to come.

Sincerely yours,

Vince L. Hutchins, M.D.
Deputy Director

Enclosure

Introduction

In February, 1988, Vince L. Hutchins, M.D., Director of the Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resources Development called together an 18-member group including organizers of parent support groups; providers of early intervention services for young children with disabilities; administrators from state maternal and child health programs and programs for children with special health needs; MCH regional program consultants; experts on health care financing; and representatives from a range of health-related academic disciplines.

The purposes of the meeting were: 1) to examine the need and opportunities for a continuum of care approach which addresses vulnerable populations of pregnant women and infants, beginning with the perinatal period, and 2) to make recommendations relative to improving linkages between the provision of perinatal care and services for these populations, including primary health care for infants and referral and the referral and follow-up to appropriate services for those with special health conditions and their families and for those at risk for health and developmental problems.

The timing of the meeting was designed to build on the momentum of a number of recent initiatives related to improving the well-being of infants, toddlers and their families.

- The Surgeon General of the United States has called for a national campaign to achieve family-centered, community- based coordinated care for children with special health care needs.

- A National Commission to Prevent Infant Mortality is collecting and disseminating data and developing recommendations.

- A variety of state initiatives are underway to prevent or reduce infant mortality.

- The Omnibus Budget Reconciliation Acts of 1985, 1986 and 1987 have offered states the opportunity for extended Medicaid eligibility to large numbers of previously unserved pregnant women and young children.

- The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) has provided funding for states to develop a comprehensive, family-oriented system of services for children from birth through age two who have or are at risk due to disabilities or developmental delays.

The following pages attempt to summarize the discussion that took place among participants in the meeting. The section on continuum of care addresses conceptual and practice issues raised by participants. The recommendations developed by the group are designed to be useful to state Directors of Maternal and Child Health (MCH) and Programs for Children with Special Health Needs (PCSHN), Lead Agency Contacts for Part H of P.L. 99-457, and other agencies, individuals and organizations that are working to respond effectively to family needs by focusing new resources and assuring effective linkage of services.

Issues in Continuum of Care Approach for Vulnerable Pregnant Women and Infants

In the absence of a universally available system of health care for children and families in the United States, a number of separate systems and specific initiatives have arisen to address the needs of targeted populations of pregnant women, infants and young children who may be at risk of poor health or poor developmental outcomes. While many of these services may provide excellent care to the individuals they reach, some do not constitute a system that assures effective continuity of care, with appropriate monitoring, referral, and specialized services as needed, to pregnant women and their children.

Several specific barriers to linkage between and among prenatal, perinatal, follow-up, referral, and early intervention services have been noted.

- Tertiary level centers, with their specialized services to treat high-risk pregnant women and high-risk infants, may not be linked effectively to state and/or local public health systems or to neonatologists and other specialists working in community hospitals. The result may be delays in referrals for appropriate care, fragmented services or failure to identify problems altogether.

- Relatively low-cost services, such as developmentally-oriented primary health care for children, or social support services, so necessary as a part of perinatal care may be in competition for funds with more expensive "high-tech" services.

- Data systems designed primarily to provide information about the incidence of birth defects, handicapping conditions or other health problems do not yet provide a universal data set nor enable states to assure the linkage of children and families to appropriate services.

- Demonstration of the effectiveness of a health care service or delivery system is not necessarily a guarantee of ongoing financial support. Widely acclaimed service delivery models that would seem to be important components in a continuum of care for pregnant women and infants, have have not yet become established in systems of care throughout the states.

Lack of specific data about the health status of expectant mothers and about the health and developmental status of young children impedes efforts to plan an adequate continuum of services and to estimate the costs involved. Both community-based service providers and state agency administrators are concerned that while their programs might meet reasonably well the needs of families and children who reach them, currently available data do not tell them what fraction of all children in their jurisdiction are being served or what fraction of children needing health and developmental services remain unserved.

Since every newborn is vulnerable to some degree and since most developmental problems cannot be predicted at birth, ongoing pediatric primary care for every child, with multiple points of entry into a system of health and other services, can be seen as a central feature of any continuum of care offering opportunities for health promotion, prevention, screening, monitoring, diagnosis and treatment. At the same time, efforts to address the unique needs and resources of every child and family cannot mean the creation of a "new" health care system for each family. The challenge to program developers and policymakers is to assure that efforts to improve care at the regional and state level, are accessible to each individual in need at the community level.

Recommendations

Maternal and Child Health Programs and Programs for Children with Special Health Needs have a tradition of service to children and families more than half a century old. Both preventive care and specialized care have been a part of that tradition. As understanding increases of ways to improve outcomes for pregnant women and to identify, monitor and serve at-risk infants, so do opportunities for effective linkage between prenatal, infant and early intervention programs.

Strategies to improve the linkage between services for pregnant women and for at-risk infants before handicapping conditions are identified must involve not only program deve- lopers but practitioners and families as well. Such strategies should address the quality of information in a system of care as well as the quality of service. The implementation of Part H of P.L. 99-457, the Education of the Handicapped Act Amendments of 1986 (see Appendix) offers MCH and CSHN agencies and personnel an opportunity for close collaboration with other agencies and with parents to explore these strategies.

- Steps toward standard data collection among agencies serving pregnant women, infants and young children offer the opportunity to yield a better understanding of the indicators/predictors of poor pregnancy and developmental outcomes, to assist in planning adequate services for populations at risk, and to estimate the costs involved. If prenatal, perinatal, primary pediatric and special health services share basic data, identified high-risk pregnancies can be linked to perinatal outcome, infants with problems can be tracked, and cross-referral can be facilitated.

- Feedback to health care providers who make referrals to tracking, early intervention and other programs helps these providers improve their practice and also builds awareness of a comprehensive system of which they are a part. Obstetricians, nurse-midwives and neonatal/perinatal nurses should receive information about the outcome of high-risk situations that they refer for follow-up or more specialized care. Neonatologists in community hospitals need more effective referral and feedback links to tertiary centers. Pediatricians and family practitioners need to know, through ongoing feedback, the progress of children they refer to early intervention services and to remain active as primary care providers. Systematic communication, rather than reliance on informal channels alone, seems critical.

- Prenatal and parenting classes should be used to inform expectant parents about the continuum of preventive and specialized services available to infants and their families. For example, one important but often overlooked opportunity for care coordination is the interface between prenatal genetics counseling and special health services. If the birth of a child with developmental problems is anticipated, planning for child and family needs can begin during the prenatal care period.

- Since virtually all births occur in hospitals, and since a number of children do not receive pediatric care from an ongoing provider, it is important to reach families with information prior to and after delivery and before discharge. Parents are often given fragments of information about screening programs, financing, birth defects registries, parent support and other issues from multiple sources. Attempts should be made to develop a means to provide such information in a more coordinated manner. Nurses and social workers who interact with parents need to have enough information themselves about community services to supplement or interpret written materials.

- Maternal and child health programs and programs for children with special health care needs can collaborate with the media and with parent groups to offer information to

families. Radio stations catering to teen audiences, for example, can direct information to adolescent parents. Informational posters with tear-off coupons can be placed in laundromats, bowling alleys and supermarkets in order to reach parents; parent support organizations can take responsibility for updating posters and making sure that coupons are available.

- Parent groups, community-based family resource programs and programs for children with special health needs have developed considerable expertise in addressing the needs of expectant and new parents for social support and information, as well as the complex circumstances of technology-assisted children and children with chronic conditions. Such organizations may offer useful guidance in creating a continuum of care for pregnant women and at-risk infants. Parent support organizations have become increasingly effective in conveying relevant information and/or in-person assistance in a timely, sensitive fashion to families in order to coordinate care with simplicity, continuity and individualization. Allocating resources to appropriate parent support organizations may add a uniquely effective component to an emerging continuum of services.

- Health-related organizations, such as the perinatal commissions and councils that were pacesetters in some states, may have a significant role to play in the development of appropriate standards of health care for pregnant women, newborns and older infants. Given a role within state Interagency Coordinating Councils under Part H of P.L. 99-457, perinatal councils might bring their expertise to bear on the many health issues confronting these multidisciplinary bodies. Representatives from tertiary care centers and HMOs as well as other health care providers should be involved in planning efforts to achieve more effective linkages between and among competing health care providers, to improve health care services children and families.

- The setting of standards of care should be followed by training, both pre-service and in-service. Professionals currently in practice may need training to acquire new skills, such as working with families to identify informal sources of support. Groups of professionals and others involved in the provision of health, education and social services, such as home health care visitors, need specialized training for work with at-risk infants, toddlers and their families, especially with a view toward assuring continuity of care and services. In order to participate effectively in new data collection efforts professionals may need training related to data collection and analysis, about findings that will assist them in identifying developmental problems early and in making appropriate service linkages.

- Efforts to assure primary care for every child should remain a high priority of all health care providers and policymakers.

- As an integral part of the effort to assure family-centered, community-based coordinated care for pregnant women, infants, young children, and children with special health care needs, each family needs an individual who serves the coordination function. While the scope of "care coordination" or "case management" may vary somewhat among service delivery systems, the goal of assisting families in order to assure access to appropriate, integrated services remains the same.

APPENDIX

Opportunities for MCH/PCSHN Involvement in the Implementation of P.L. 99-457, the Education of the Handicapped Act Amendments of 1986

Just as the passage of P.L. 99-457 has provided the occasion for intensified collaboration between the Office of Maternal and Child Health and other agencies at the federal level, so implementation of the law at the state level provides new opportunities for closer collaboration among Maternal and Child Health agencies, Programs for Children with Special Health Needs and other agencies working with infants, toddlers and their families. Designated "lead agencies" for services to children from birth through two years of age ("Part H") and their families are listed below. In fifteen states, health departments were designated to serve in that capacity.

Designated Lead Agencies

Education: Alabama, Colorado, Connecticut, Delaware, Florida, Illinois, Iowa, Louisiana, Michigan, Minnesota, Missouri, Nebraska, New Hampshire, New Jersey, Oklahoma, South Dakota, Tennessee, Vermont, Guam, Mariana Islands, and Puerto Rico

Health: Alaska, Hawaii, Idaho, Kansas, Massachusetts, Mississippi, New Mexico, New York, Ohio, South Carolina, Utah, Washington, West Virginia, Wisconsin, Wyoming, American Samoa, and the Virgin Islands

Mental Health/Mental Retardation/Developmental Disabilities: Arizona, California, Indiana, Montana, Oregon, Virginia

Human Services/Human Resources: Arkansas, Georgia, Kentucky, and Washington, D.C.

Interagency Coordinating Committee: Maine, Rhode Island, Texas

Public Welfare: Pennsylvania

Governor's Office of Children and Youth: Maryland

In all states, Interagency Coordinating Councils provide a mechanism for representatives of agencies, parent groups, providers, educators and others to help shape a comprehensive system of services for eligible young children and families.

The fourteen components listed in this legislation as essential to a comprehensive system of care include a number of areas in which the expertise and perspectives of Maternal and Child Health Programs, Programs for Children with Special Health Needs, and other members of the health care community can be particularly valuable. The issues of care coordination, public awareness, data collection, training, and standards of care, among others, discussed in the body of this paper are similar in many instances to the needs addressed by the components of a service system as outlined in P.L. 457, Part H. In this appendix, the service components of a state system as described in Part H are used as points of reference, to facilitate discussion among MCH, PCSHN, and other agencies.

1. **Defining the population to be served**

The broad perspective of maternal and child health agencies and of public health personnel in general can be very important in helping states to define the population to be served under P.L. 99-

457. A number of state health departments are urging the adoption of broad definitions of developmental delay and the extension of services to "at risk" populations. Even if states decide on narrower eligibility criteria, the process of arriving at a definition can stimulate statewide discussion of how to meet the needs of infants, toddlers and families who remain unserved. As health professionals remind policymakers of the uncertainties of risk identification in the early years of life, they will also have an opportunity to stress the importance of universally accessible primary health care for young children, as both a preventive measure and an ongoing opportunity for early identification of developmental problems.

2. Multidisciplinary evaluation

Standards for nursing diagnosis as well as guidelines that have been developed by physicians and other health professionals can offer useful guidance as states develop standards for multidisciplinary evaluations of children and families. Health professionals and others will need to keep in mind the family-centered focus of P.L. 99-457 and the emphasis of the legislation on identifying family and child strengths. The "conveyor belt" experiences that have often awaited families in tertiary care centers or the drawn-out process of multiple evaluations in dispersed specialty clinics is not one to be encouraged.

3. Individualized Family Service Plan

The health status of child and family and the primary health care needs of child and family should be reflected in the IFSP, which is seen as the cornerstone of the legislation. The special health care needs of an infant or toddler must also be recognized, even if medical care itself will not be provided through P.L. 99-457 auspices, since family attention will necessarily be focused on the process of obtaining appropriate health care. Since care coordination or case management is closely linked with the development and implementation of the IFSP, the possibility of funding care coordination through Medicaid for eligible children and families must be considered. For many families, a nurse or, less frequently perhaps, a physician may be the most appropriate choice to work with the family as care coordinator.

4. "Child find" system

Health professionals and staff of Maternal and Child Health Programs and Programs for Children with Special Health Needs are aware of the need for multiple opportunities to identify high-risk pregnant women and high-risk newborns and other children. Once again, the broadest possible access to prenatal care and to primary pediatric care may prove the surest route to prevention of disability as well as to early identification of developmental problems. Since virtually all mothers and infants are seen in health care facilities, at least at the time of delivery, health professionals should be closely involved in the design and implementation of child find initiatives.

5. Public awareness

Public awareness efforts need to include: 1) systematic efforts to inform health professionals themselves as well as members of other disciplines concerning the variety of health care resources available to infants, toddlers and their families; 2) comprehensive yet easily understood information for families, delivered at the time of childbirth and reinforced thereafter; and 3) information to policymakers about the importance of primary as well as specialized health care and developmental services for pregnant women, newborns, infants, toddlers and their families.

6. **Central directory**

The complexity of health care service delivery and financing mechanisms in any state, not to mention those services that are organized regionally, suggests that a central directory should describe those primary and specialized health care services available in a state, discuss eligibility for subsidized care, and also list special resources such as regional perinatal centers and University Affiliated Programs. Information about private health insurance that is regulated by the state might also be included. As compilers of the directory consider "experts" for inclusion, they should look at the entire range of public, private and academic health expertise available in the state.

7. **Personnel development**

Pre-service, in-service and continuing education offer opportunities to involve health professionals from a broad range of disciplines. New interest in serving young children with disabilities and their families has been stimulated among private sector pediatricians by P.L. 99-457; opportunities should be seized to reach this group through continuing education initiatives. The skills of many health professionals in areas of assessment, collaboration with families, and interdisciplinary collaboration can be enhanced through a variety of training approaches. Parent organizations can prove to be a valuable training resource for health professionals at all levels.

8. **Single line of responsibility in a lead agency**

While every state has now designated a lead agency responsible for activities under Part H of the Law, it will be possible to change the designation if appropriate. Health agency personnel, health care providers, families and all state agencies serving the 0-2 population will need to evaluate the experience of implementing P.L. 99-457 in each state in order to make recommendations about the most appropriate lead agency over the long term.

9. **Arrangements for early intervention services**

The experiences of Maternal and Child Health Programs and Programs for Children with Special Health Needs in providing or contracting for care through community agencies, private providers, tertiary care centers, regional facilities and other means should provide useful models for states, particularly in the area of individualizing services to meet unique child and family needs.

10. **Standards for preparation and training of personnel**

Since it is likely that community-based early intervention services will be provided by multidisciplinary teams, it is important for health agencies and health professionals to consider how health expertise and information can be made available to community programs and the families they serve at the same time that links are maintained to families' primary health care providers. Health advisory committees, similar to those used in the Head Start program, may be useful. If case managers or health coordinators of early intervention programs are not themselves health professionals, attention should be paid to the kinds of health expertise they do need in order to address the range of children's and families needs.

11. **A system for compiling data**

As indicated in the discussion above, the experience of data collection among health departments and public health professionals in general can be extremely helpful in the development of a state data collection system to document the need among infants, toddlers and their families for early intervention services, the numbers served, types of services provided and other information.

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